

To: Representative Lasee, Chairperson and Committee Members of the
Assembly Committee on Insurance
From: Alicia, Janko and Oliver Boehme
Date: February 25, 2008

Our child, Oliver Boehme, was born with bilateral sensorineural mild to moderate hearing loss. He was identified as having potential loss upon discharge from the hospital after an eleven-day stay in the neonatal intensive care unit. A few months and numerous long tests later, he was officially diagnosed. We were informed during the testing process that our insurance company was not likely to cover the cost of hearing aids for Oliver.

The cost of hearing aids for Oliver totaled around 4,000 dollars, and despite the fact that our insurance company at the time did contribute to the cost, it was a financial burden for our family. We would like to point out that the price of the aids themselves is not the only cost that families encounter. There are costs associated with maintenance of the aids, creation of ear molds¹, and fixing the aids if they break.

You will hear many compelling stories from families today. We would like to focus on five major points that summarize some of the main arguments you hear today and illustrate why you should vote in favor of this bill.

1. AB 133/SB 88 is fiscally responsible

- a. Research shows that proper intervention (i.e., hearing aids or cochlear implants) that occurs early in the life of the child decreases or eliminates special education services that a child might need. A savings of between \$5,000 to \$10,000 per child per year² and 1 million dollars per person over a lifetime can be actualized³. So, it costs more in the long-run to pay for the consequences of children who do not get immediate and proper hearing intervention.

- As an aside, I have heard many compelling stories from families who have children with hearing aids and cochlear

¹ The hearing aid fits behind the child's ear and there is a tube that goes from the aid and attaches to plastic piece that fits snugly in the ear. As the child grows, they outgrow the mold. Therefore, new molds need to be cast and created. There is a cost associated with this. We are charged 80 dollars.

² Yoshinago-Itano, Christie, and Gravel, Judith. The Evidence for Universal Newborn Hearing Screening. American Journal of Audiology, December 2001; 10:62-64.

³ These figures are based on 1993 numbers as reported by Johnson, J.L., Mauk, G.W., Takekawa, K.M., Simon, P.R., Sia, C.C.J., and Blackwell, P.M. Implanting a statewide system of services for infants and toddlers with hearing disabilities. Seminars in Hearing. 1993; 14: 105-119.

implants across the state. One that sticks out in my mind is a parent who could not afford to pay for hearing aids for her child and was told by a professional that she should allow her child to become significantly developmentally delayed so that she would qualify for the state to pay for the cost of the hearing aids.

- b. This is not an expensive bill. There were only 95 babies identified by the newborn hearing screen in 2007. It is estimated that around 200 children in total are identified across the state each year.
- c. Not all children who need hearing aids or a cochlear implant are covered under insurance affected by this bill. Only 29 percent of the population is commercially insured. The bill would not impact children covered under self-insured plans (36%), or those who are covered under public insurance (30%).
- d. Fiscal estimates on similar bills reveal that the increased cost can be fewer than 2 dollars per year per customer. ⁴

2. There is no logic to the current lack of coverage by insurance companies.

- a. Why don't insurance companies pay for hearing aids and cochlear implants for children? This is a good question. I would love for a representative from the insurance industry to address that question today. I have heard it is because insurance companies consider them to be "cosmetic" in nature. This is absurd. Hearing aids and cochlear implants are devices that are proven to be effective. In addition, insurance companies routinely pay for other cosmetic-related expenses for individuals. Our insurance company, for example, pays for cosmetic laser treatments for the removal of birthmarks and other birth defects of a child, wigs for cancer patients who have lost their hair in treatments. Additionally, our insurance company pays a whopping \$15,000 for individuals to receive a sex change.
- b. Health insurance companies also regularly pay for a multitude of other medical expenses. If someone cannot walk, insurance pays for a wheelchair. If someone needs prostheses, it is covered by insurance. What is different about hearing aids and cochlear implants that would justify omitting them as covered items?
- c. Our insurance company pays for everything surrounding Oliver's hearing loss. They pay for hearing tests, other tests to rule out possible syndromes, genetic testing, tubes to ensure there is no further hearing loss from ear infections, eye exams, and virtually anything else related to his hearing loss. In fact, our insurance company was charged around \$11,000 towards hearing related care over the first year of his life. It does not make sense for the insurance company to take responsibility for all these expenses and not the device itself that allows him to hear.

⁴ <http://www.drnh.org/Hearingaid.htm>

3. The cost of hearing aids and cochlear implants places a financial strain on families.

- a. You have heard the stories of how insurance companies have discriminated against families with children who are deaf and hard of hearing in our state. According to a survey completed by the Wisconsin Chapter of Hands and Voices, the majority of insurance companies are not paying for the cost of hearing aids. Fifty-four percent of the parents surveyed did not have insurance that covered any of the cost for hearing aids for their children. The average out of pocket expense for these parents was \$4,100. Parents with partial coverage for hearing aids did not fair much better; their out of pocket expense averaged \$3,727.
- b. There are few, if any recourses for many families, and it is the children who suffer the consequences. There is no supplemental insurance offered to cover hearing aids or cochlear implants similar to supplemental dental or vision insurance.

4. The state of Wisconsin has set precedence that people's ability to hear is critical.

- a. Clearly a number of people at the state feel that hearing is important to be covered. So why doesn't the state take a stand to ensure that our child is covered too?
 - Individuals covered under the **state insurance plan** have hearing aid and cochlear implant coverage regardless of age;
 - **prisoners** who reside in our state penitentiaries have hearing aid coverage regardless of age;
 - individuals who have **Medicaid** are covered regardless of age too; and
 - so are individuals covered under **Badgercare**.
- b. Many others states such as Connecticut, Kentucky, Louisiana, Maryland, Minnesota, Missouri, Oklahoma, Rhode Island and Maine all have laws that require insurance companies to pay for hearing interventions for children. Most of the laws cover children under the age of 18. In addition, there are a handful of states like Pennsylvania and possibly Iowa that provide automatic coverage for children who are deaf and hard of hearing for hearing aids and cochlear implants under MA.

5. The amendments should be passed

- a. When considering AB 133 also pass the two amendments introduced for this bill. One amendment would increase the age of children covered to those under the age of 11. Increasing the age will ensure that a child develops necessary speech, language, and social skills. Ideally however the bill would cover children up to the age of 18.
- b. The second amendment takes the word "severely" from the bill. The bill states that a child will be covered who is "deaf or severely hearing

impaired". This language excludes children, like Oliver, who need hearing aids to acquire language and speech, but who don't have the label of being "severely hearing impaired."

Thank you for your consideration of this bill. We urge you to vote in favor of this bill immediately so that it can be heard and passed on the Assembly floor.

To: Representative Lasee, Chair, and Members
Assembly Committee on Insurance
From: Alicia Boehme, Disability Rights Wisconsin and Survival Coalition of
Wisconsin Disability Organizations
Subject: **Assembly Bill 133/Senate Bill 88**

Make a commitment to children who are deaf and hard of hearing in Wisconsin

I am testifying today wearing two hats. First, I am a parent of a child who is hard of hearing. Oliver, my son, is 15 months old and has been diagnosed as having bilateral mild to moderate hearing loss. He uses hearing aids to develop language and speech as well as to interact socially.

I am also testifying as an employee of Disability Rights Wisconsin (DRW). DRW is the designated Protection and Advocacy organization for people with disabilities in Wisconsin. I am also here representing the Survival Coalition of Wisconsin Disability Organizations, which is network of over forty disability organizations across the state.

Oliver was identified as having potential hearing loss upon discharge from the hospital when he was born. Most hospitals in Wisconsin screen newborns to identify potential hearing loss. The State of Wisconsin made this very important commitment to children (see Chapter 253.115 of the Wisconsin Statutes), and the program has been extremely successful in identifying babies who may be deaf or hard of hearing and referring families for further testing. Identification, however, is half the battle. Intervention is the other half. And the reality is that families in Wisconsin are having trouble paying for hearing aids and cochlear implants for their children.

Currently, insurance companies are not required to cover any cost associated with hearing aids or cochlear implants for the children of our state. Approximately 200-300 babies are born each year in Wisconsin who are deaf or hard of hearing. According to a survey completed by the Wisconsin Chapter of Hands and Voices, the majority of insurance companies are not paying for the cost of hearing aids. Fifty-four percent (54%) of the parents surveyed did not have insurance that covered any of the cost for hearing aids for their children. The average out-of-pocket expense for these parents was \$4,100. Parents with partial coverage for hearing aids did not fair much better; their out of pocket expense averaged \$3,727.

It does not make sense to identify babies who are deaf and hard of hearing and not intervene. Research shows that when children do not receive early intervention, there are significant social and economic costs. Hearing loss impacts language and speech development, social interactions, and academic achievement. According to researchers, early intervention can provide savings of between \$5,000 - \$10,000 per child per year in

reduced or eliminated special education services¹. And over a lifetime, early intervention can reach a savings of about 1 million dollars per person².

Families in Wisconsin are struggling to pay for interventions, and there is a true need for insurance coverage of hearing aids and cochlear implants. Here are just a few testimonials from families across the state³.

- “I knew I could not afford the \$4,000 for new hearing aids even with the \$1,000 being covered by insurance for the aids themselves...Since I have 2 deaf children, I really need to get outside support...”
- “We are still paying the credit that we had to borrow using our credit card company.”
- “Without BadgerCare, there is no way our family could have provided Isaac with the necessary hearing aids and services he has needed.” (Most families do not meet the eligibility criteria for BadgerCare, and therefore BadgerCare is not a resource that most families can access to cover the cost of hearing aids and cochlear implants).
- “I hate the thought of sacrificing what is best for my child because of money, and yet there may be no other option if insurance companies do not help cover these medical expenses.”

On a personal note, Oliver’s insurance company paid for only a portion of the \$4,000 cost of the hearing aids, forcing us to struggle to pay for the remainder.

Disability Rights Wisconsin stands behind Wisconsin Families with children who are deaf or hard of hearing and need this vital coverage.

Suggested Amendments

On behalf of myself and DRW and the Survival Coalition, I strongly recommend that the committee commit to the amendments that have already been incorporated into SB 88. First, the bill should increase of coverage to children under 11 years old.

Second, the bill states that a child will be covered who is “deaf or severely hearing impaired”. This language unintentionally cuts out children, like Oliver, who need hearing aids to acquire language and speech, but who don’t have the label of being “severely hearing impaired”. Oliver has been diagnosed with mild to moderate hearing loss and requires hearing aids. Without them, Oliver would not develop these skills properly just like a child diagnosed with “severe loss”. We recommend that that the term “severely” be removed from the bill.

I ask you to pass this very important bill and make a commitment to children who are deaf and hard of hearing in Wisconsin.

¹ Yoshinago-Itano, Christie, and Gravel, Judith. The Evidence for Universal Newborn Hearing Screening. American Journal of Audiology, December 2001; 10: 62-64.

² These figures are based on 1993 numbers as reported by Johnson, J.L., Mauk, G.W., Takekawa, K.M., Simon, P.R., Sia, C.C.J., and Blackwell, P.M. Implementing a statewide system of services for infants and toddlers with hearing disabilities. *Seminars in Hearing*. 1993; 14: 105-119.

³ These testimonials were collected by the Wisconsin Chapter for Hands and Voices.

To: Committee on Insurance
Date: February 19, 2008
Subject: Assembly Bill 133

Hello. My name is Angela Klitzke and this is Chloe Jane Klitzke. Chloe has mild to moderate hearing loss and I am her mother. I am here to testify in favor of Assembly Bill 133.

Chloe was born in July 2006 in Reedsburg. What a wonderful day for such a beautiful, healthy girl to be born! Chloe is now 18 months old. Chloe is the youngest child in our family. She has an older brother, Connor, who is four and a sister, Cassidy, who is three. Yes, our house can be quite busy!

Let me take you back to the beginning of our amazing journey with our daughter. During our hospital stay Chloe had been tested for hearing loss. To our family, this was just a routine part of having a baby. Both of our other children were tested for hearing loss at birth and passed this test right away. Chloe did not. When we were discharged from the hospital after her birth we were told we should come back in for Chloe to take her newborn hearing screening, again. At this point, I was not worried about this as her birth was a c-section and often fluids can be in the baby's ear canal. Approximately two weeks later I took Chloe back to the maternity area of our hospital to take this test again. Again, Chloe did not pass this test. At this point I was getting a little bit worried. I can vividly remember sitting in that glider rocker snuggling my newborn with tears running down my face. A day I will never forget. We left the maternity area to go directly to see our pediatrician. He checked to be sure that there was no fluid in her ears, which there was not. He then recommended that we see Dr. McMurray, a pediatric ENT at UW. We saw Dr. McMurray a couple weeks later. Chloe also saw an audiologist. When Chloe had this hearing screening done in Madison she did not pass the test at all. At this point we were terrified, wondering what is in store for us? We had a more detailed test at the UW hospital about two weeks later. (We were very lucky to have all of this happening as quickly as it was, although to us, not knowing felt like a lifetime.) After this test we left the hospital feeling quite overwhelmed. We were told that Chloe had hearing loss.

My husband and I decided that we would do whatever we needed to do to get Chloe hearing aids as soon as possible to help her to be the best that she can be. However, we were not aware that insurance companies in Wisconsin do not cover this type of health need. My question to you is: "Why do insurance companies cover not only typical health needs, but go as far as covering atypical health issues that are at times self inflicted, but do not cover hearing aids, molds, and other hearing related needs?" My husband and I have jobs outside of the home, he is an engineer and I am a teacher. We work very hard and have good insurance through work. Still, the financial burden of hearing aids for our daughter has been overwhelming since even good insurance does not cover this. Because Chloe was so little she needed to have the "Cadillac" of hearing aids. The hearing aids alone cost almost \$5000.00. Keep in mind, that cost is solely the cost of the hearing aids. That does not include the molds, which keep the hearing aids in her ears or the visits to the ENT or the audiologist. Up to this point in Chloe's short life she has had 8 pairs of ear molds. Each ear mold costs \$109. That means that just the molds alone have cost us \$1744.00. As you can see this can be a financial burden for a family. The cost of hearing loss can add up quite quickly. In a sense, this is adding insult to injury. When paying for health insurance one would expect this to be covered. It was a shock to our family that in the state of Wisconsin, this is not the case.

As I said, I am a teacher, and work every day with young children. I currently teach third grade at a parochial school, however, I am certified to teach special education. I am aware of what type of delays can accompany hearing loss.

Some of my students struggle to read and I know what a burden this can be for these precious children. Without Chloe's hearing aids she would struggle more with reading. How? Well, you see, as an infant they are learning speech and language each and every day. If she cannot hear the sounds that we are speaking to her, she cannot learn to speak. In turn, she will have a more difficult time learning to read. This could then compound into struggling with other subjects. Ask any of my third graders and they will tell you the amount of reading that they are expected to do at this early elementary age. If a student struggles to a certain extent they will then need special education services and so on. It costs far more in the long run to support and educate individuals who do not receive the appropriate early intervention than to provide it as soon as possible.

Chloe has had her hearing aids since she was three months old. Her speech is developing within the average range that it should be. She says: baby, Mama, Daddy, hot, no, and a few other words. In fact just the other day she said thank you! Chloe also uses some simple signs to communicate with us. We are very fortunate that we learned of Chloe's hearing loss at such a young age in order to intervene as soon as possible to help to maximize her language and speech. Although it was a financial burden and continues to be, we were also fortunate that we were able to afford hearing aids for Chloe; however, many families are not as fortunate.

I feel that it is important that Amendment 1, to increase the age to cover children under the age of 11, is passed to match the Senate version of the bill. In order for Chloe to be covered by this bill it is also important that the word "severely" be left out so that it covers all children who are certified as deaf or hard of hearing. The Senate has already been amended to take out the word: "severely", so please do the same.

I would like to thank you for your time. It means a lot to my family and I that you take the time out of your busy schedule to discuss an important matter such as this. For Chloe, and other precious children just like her, I thank you for understanding why insurance companies should cover the cost of hearing aids and cochlear implants for all children who are deaf and hard of hearing. So, please, for Chloe and all other precious children, please vote in favor of the bill.

**Testimony in support of Assembly Bill 133:
Insurance Coverage for Hearing Aids and Cochlear Implants for Children**

I am the parent of a 12-yr old daughter, Claire, who has a mild to moderate bilateral hearing loss and wears hearing aids. I am writing in support of Assembly Bill 133, requiring insurance coverage for children who need hearing aids & cochlear implants. I also support the amendment that expands this bill to cover children up to the age 11 and encourage you to amend it to cover ****all**** children who are certified as deaf or hard of hearing (not just "severely" hard of hearing).

Claire has always had excellent health care, but her hearing loss went undetected until she was in 2nd grade (8 years old). It is believed that she may have had this hearing loss since birth, but because she worked very hard to compensate, no one (including her) realized that she was not hearing everything. By the time this loss was detected, Claire was really struggling both socially and academically. She still continues to receive extra support at school due to her hearing loss.

Although Claire's hearing loss is described as "mild to moderate", there is nothing mild to moderate about the effect hearing aids have had on her life, including but not limited to her self-esteem and ability to function as a competent, independent person.

The diagnosis of a hearing loss came as a complete surprise to us. We had suspected the possibility of learning disabilities, but hearing loss wasn't even on our radar screen. The clear and immediate solution was to ensure that our daughter received services from a competent pediatric audiologist and to get her fitted with hearing aids. We were shocked when we learned the cost of the hearing aids.

Fortunately for us, my spouse's insurance as a state employee covered 1/2 of the cost of each hearing aid, up to \$1000 per aid. Even with this coverage, however, we had to suddenly figure out how to come up with \$2000 (our "co-pay" for the hearing aids). What could we do? Our daughter had been struggling for 8 years with an undiagnosed hearing loss - for 8 years, she had been missing out on so much in her environment, including academic and social information and opportunities. This wasn't like a car repair we could just put off. So we did what most folks would do - we put it on our credit card & then worked hard to pay it off.

But what about the families that don't have health insurance that covers even part of their costs? What about families that don't have credit or that put it on their credit cards, only to struggle to pay off that debt?

It's been 4 years since Claire got her hearing aids & they have changed her life. She still has struggles, but now she has better access to the world. And again we're the lucky people: her hearing aids haven't broken or worn out yet; if they do, her health insurance will cover up to 1/2 the cost of the aids once every 3 years, so we can get some coverage. But let's face it, the prospect of paying \$2000 or more is not something we relish.

And I haven't even talked about the on-going costs of batteries (which must be replaced every two weeks) and replacing ear molds whenever she out-grows them or they tear (approximately \$160 a pair). These costs are not covered by insurance. Additionally our visits to the audiologist and the ear doctor 1-2 times a year are covered by our insurance, but for other families, this is an additional out-of-pocket expense that greatly adds to the family burden.

So, please pass this bill, with the amendments I have described. It's the right thing to do. If you have any questions, please feel free to contact me by email at scgwis@gmail.com or by phone at 608-345-4761. Thank you.

Deb Wisniewski
21 Corry St., Madison WI 53704

Hello. My name is Laurie Nelson and I am Peyton's Mom and we are here to support AB 133, with the same modifications as made to Senate Bill 88. Our daughter's hearing loss was diagnosed shortly after her second birthday. Our insurance did not cover any costs for hearing aids. My husband and I have had to bear this financial burden totally out of pocket. I am not talking about a couple hundred dollars. Each pair of hearing aids cost us between \$3-4,000 and we have purchased three pairs. The Clinic we have used did not offer a lengthy payment plan either. We had to pay 1/2 down and pay the balance in 3-4 months. WOW! It has been an extreme financial burden, but what were we supposed to do? She's our daughter!

Peyton is truly our inspiration and hero and we firmly believe we need to keep up with the fast changing pace of technology and get her new hearing aids every 3-4 years. Desperate times have called for desperate measures. Have you ever had to pay for your groceries with a credit card? Have you ever had to eat meals at your parents' house because you didn't have enough money to put food on your own table until your next paycheck? We have. Fortunately, we were lucky. We had the support of our family and scraped by financially to get through it. Other families are not so lucky. **Getting hearing aids or a cochlear implant for your child should not be a desperate measure for any family to have to bear financially.**

Hearing loss is a sensory issue. All people with hearing loss have the basic fundamental right to access language and communication. Hearing aids and cochlear implants are part of that access. Without that access, children may develop delays in their language skills, which could lead to delays in their comprehension skills, which could then lead to frustration and possible behavioral issues, and then perhaps to depression in our youth. **Children should not have to wait to get access to the world around them while their parents make arrangements, or find assistance, for funding for hearing aids or CIs. The effect this can have on our kids would be profound and extremely detrimental.**

Hearing aids are NOT cosmetic. They are what give our deaf/hh kids ACCESS to the world around them. This bill needs to be passed so that all kids who have a hearing loss can get access to their worlds. Families should not have to bear that overwhelming financial burden and our children should not have to pay the price.

I am requesting two amendments to AB 133. One that increases the ages of children covered to match the Senate version of the bill – which is age 11.

The other is that the bill inadvertently restricts children who are covered to those who are "certified as deaf or *severely* hearing impaired. Please remove the word "severely" so all children who are deaf or hard of hearing can be covered.

Thank you for holding this hearing and please vote in favor of this bill! Our kids are counting on you!

Laurie & Peyton Nelson
lspnelson@verizon.net

Hi. My name is Peyton Nelson and I am here to support Assembly Bill 133. I am hard of hearing. I wear hearing aids in both of my ears. My hearing aids are **very** important to me. They help me understand what people are saying. They help me hear environmental sounds to keep me safe. They help me to understand conversations with my peers. I have a lot of friends, so my hearing aids help me to know what it going on at my school. I wear an FM system at school which helps me hear my teachers too. If I did not have my hearing aids or FM, I would not be able to understand very much! That would be very frustrating.

I hope that you will pass this Bill so that all kids with hearing loss like me can get hearing aids and that their Moms and Dads don't have to pay for them. That's why I am here, because this is very important.

Moms and Dads should not have to pay for hearing aids.
Insurance companies should!

Thank you!

Gentlemen, My name is Matthew Hanson and I'm a Freshman at Hartford Union High School. I'm severely profounded deaf which means that im close to the borderline of being completely deaf.

When I was born my parents have convinced me to read and speak English. Without my hearing aids there's no way that I could've done that in my life. I have to say thank you to my parents for allowing me to get hearing aids because I would probably be a mute right now if it wasn't for them. They had me put my hand on their throats and lips and I had to listen to them in order to talk English and without hearing aids I couldn't possibly do that. Shortly after that I started reading, but I also had to listen to my parents and teachers in order to be able to read. How can I go to school if I can't hear without my hearing aids or how will I receive my instructions from my teachers while I'm attending school everyday.

School is where I met many new friends and was able to understand more about the hearing world. Meeting friends was a tough thing at first, but with the hearing aids, I was able to blend in with the rest without a problem. Speech class helped me more with the tougher English and then the kids were able to understand me more and I was more involved with school activities. I'm on the Hartford basketball team and was able to understand the plays by reading the signs and reading their lips. My coaches can communicate to me because of my hearing aids and it makes it easier to understand what their staying then without them.

Hearing Aids are not just objects, they are things that makes a little deaf kid's life able to make it easier to live. If I didn't have hearing aids I'd probably end up having to live on government funds because I wouldn't be able to read or hear what you people are trying to say to me. Hearing aids allow little kid's to have all the opportunities that hearing people have in life, but your stopping that from happening because you just don't want to pay for it. To me, it's important that these kids are abled to have hearing aids so that it will open up their worlds and they will have a chance to make friends and be able to talk like a regular human being. Without hearing aids babies are missing one of the most important things in the world and that's the ability to hear. Also, they will miss out on the ability to communicate because how else are they suppose to understand what we are talking about.

I am successful today because of the help from my friends, family, and being on the basketball team. They all have helped me to accomplish something in life and that's what makes my life worth living for. My parents have helped me accomplished being able to hear and communicate with others and that's what thrives me everyday to see the next day. My friends have helped me with school and helped me be able to survive to the next day and they also helped me communicate better on the streets. My basketball team has helped me be able to become a team player and how to communicate with others so they can understand me.

My family has helped me so much throughout my life because they got the hearing aids for me, but they didn't have to. They choose to because they knew it would make my life better and help me become a better person. They did a very good job because like all my friends don't even consider me a deaf person because I don't have that much of a trouble understanding them and they don't have much trouble understanding me. I would like to say thank you to my parents and I love them very much for doing such a wonderful thing for me.

To you gentlemen, I just have one question for you and that is what will you do if someone in your family turned deaf or you turned deaf when you got older and needed hearing aids, but insurance wouldn't help you at all?

Thank you for you time Gentlemen

Good afternoon. I am here today to speak on the behalf of my students and their parents to ask you to please pass this bill into law. Many of the families that I work with suffer financial hardship because the insurance they have will not cover hearing aids. They have to pay thousands of dollars out of their pockets for their child to hear. One family in particular has two boys with a bilateral loss. This means that they have had to purchase four hearing aids at approximately \$2,000 per ear. This does not include annual maintenance on the aids such as recasing and fitting for new earmolds. I have seen families max out their credit cards paying for hearing aids and then wonder where they will get the money for necessities (i.e. clothing etc). Christmas is usually a very difficult time of year for most of my families

The statistics for unaided children is alarming. They are twice as likely to end up in the ER as children with normal hearing. They are ten times as likely to be held back a grade. 9% of children diagnosed with ADHD actually have an unaided hearing loss. As adults these children will make eight to twelve thousand dollars a year less on average, even after adjusting for geography and education.

The National Institute of Health have estimated that the cost of not providing aids or cochlear implants to deaf infants is approximately \$1 million dollars over that child's lifetime. Most of that cost (special education, Medicaid services, lost tax revenue) is born by the states.

There are about 10 states currently mandating coverage for hearing aids. The average pair of digital hearing aids(which is what children really need because of all the background noise associated with classrooms) is \$5800 and needs to be replaced every four – five years.

As an educator, unfortunately I have also seen parents unable to pay for hearing aids and the child goes unaided or with only one hearing aid. Therefore, my students miss much of what is being taught in school. I ask you again today to please support this bill and help my students and their families.

Sue Whooley
Teacher of the Deaf & Hard of Hearing CESA #2
swhooley@deforest.k12.wi.us
(608) 842- 6183
404 Yorktown Road
DeForest, WI 53532

Franz Backus - In Favor of AB 133

Good morning Chairman Lasee, and members of the committee. Thank you for this opportunity to share my reasons in support of AB 133.

You will hear from parents who have struggled with equipping their children to join the hearing world in which you and I live. These children and their parents have poignant and real stories to hear. Having been hard of hearing since my youth, and a Cochlear Implant recipient, I too have a story about the *challenge of learning when you can't hear*. But the story that you will hear from me is about those whose parents could not be here because they are working, can not take time off, and can not afford hearing instruments for their children. It is also about the taxpayer who will foot the bill of educating the undeveloped mind of each child who is held captive in deafness at the time he or she needs to hear to learn speech and socialization skills. I am going to tell you the economic impact of the practice of denying hearing Instruments, and Cochlear Implant insurance coverage.

By way of background the following points should be considered.

- There are about 200 children born in Wisconsin each year who are profoundly hard of hearing or "deaf" (of the "deaf" about 1/3 can never be helped by aids or Cochlear Implants)
- Children from families who do not have income are eligible for implants and hearing aids from existing health programs in the state (title 19)
- Children from families covered by state employee health care programs also have access to aids and Cochlear Implants
- The cost of this aid and Implant coverage for example is very low, the State of Minnesota employee coverage for all subscribers was estimated to be \$0.25 per policy per month, and Wisconsin added aids and implants for all covered by policies, not just infants, by increasing co-pay for emergency room visits by \$15.00 per visit with no impact on Wisconsin taxpayers.)
- The only folks not covered, and we are down to well under 100 per year, are those who work and thus have too much income.
- An alternative for these parents who are not covered is to give up work (income) to qualify for title 19 type grants, a prospect that no one desires.

As an economist I am sorry not to have the exact number of children that would be affected, but it is very small and that is a problem. I can however tell you in Wisconsin public education there are currently 1,189 children under 11 years old who are defined as deaf or hard of hearing. Since students continue in public education until they graduate from high school one could estimate there are about 4,000 in our schools. This is a small but expensive number where each student in separate schools hides the impact from the public, but costs taxpayers thousands of dollars each year they are in school. (Please read the addendum for more information). These students are in public schools for an average of 14 years, so it does not take too much math to

conclude a savings of say \$5,000 for aids or even \$60,000 for a Cochlear Implant early in life is multiples less than the costs to taxpayers of attempting to repair the damage of denying hearing aids and Cochlear Implants. Correctly fitted high-powered hearing aids and cochlear Implants early in life help prevent speech and learning disabilities and with them the attendant cost to the taxpayer.

The insurance industry has no incentive to add coverage that has a very low chance of occurring as it does not produce many denials, and is seen as a cost savings. The incidence of well less than 200 claims a year is too low to even offer a rider to cover hearing loss for a specific number of years on newborns, so even if a family wanted to buy a policy when they were adding to their family they would have great difficulty doing so. It would be comparable to trying to buy a 100-day term life policy when being deployed to a war zone.

And then there is **the taxpayer** who is providing incentives to families to quit work to gain "title 19" coverage to take care of their child, and who fund schools who get the detritus of the non-coverage. There are many experts who can discuss in real (not theoretical terms) the results of denying hearing to babies and very young children and you will hear from them. In graphic terms however denying hearing in the early years is in a very real sense equivalent to binding a child's hands for the first 5 years of life and then sending him/her off to shop class. No amount of fixing or remediation is going to correct the damage, but the Wisconsin Taxpayer is going to pay to attempt to, under the real and honorable effort to leave no child behind, which has been Wisconsin's rightful motto for a long time.

In short you hold in your hands the power to send possibly a 100 severely handicapped children to Wisconsin public schools each year or to send these same children reasonably enabled to attend school as normal (non-handicapped).

I am aware that all folks that petition you claim their bill is good for the state and or that it saves money, and as an economist I have made my share of such eloquent arguments using theoretical data. There is no theory that denying hearing in the earliest years cripples children, it is that simple and the effect on our schools and taxpayers is real, so we may disregard the lifelong effects on the needlessly deaf child when they reach adulthood and pay less taxes and contribute less to society than the fully educated and enabled.

Please consider the taxpayer on this issue, and that the insurance industry on an equal footing would absorb or displace the very small sums paid to cover the few infants they would find in their covered. This is a small constituency very large impact bill. I hope now that you have been given the nature of this bill, you will send it to the assembly with your full endorsement as good public policy. Thank you for your consideration.

Franz Backus (Economist)

Addendum

Starting with 200 births a year of severely hearing impaired children, and subtracting those covered by Title 19, state of Wisconsin employee covered, and those children for whom there is no possible intervention, it is possible that fewer than 100 events a year are covered by AB133. I do not have data on how many children suffer severe permanent hearing loss from childhood diseases, which is why I cannot reasonably estimate the actual number. It is worth noting however that insurance generally covers the diseases that can cause deafness and that the coverage stops with the drugs as if the child is cured, and this is a cruel event that hurts more than the families and the child.

The cost of providing special education to students who are deaf or had of hearing throughout their school career is impossible to generalize. I am aware of a report by AG Bell to identify the cost of educating children who are deaf as about \$420,000. This report has been widely used, but is over 12 years old and simply cannot account for the differences of children, the degree of damage to each child, and different wage contracts for professional staff.

It is not difficult however to believe that it would cost more than \$15,000 per year, per child, which produces additional taxpayer burden of \$210,000 for schooling. Given the cost to an insurance group of \$5,000 to \$60,000 for an implant and it is clear that good public policy would be to require coverage.



Deaf Bilingual Coalition

Sign From the Start. Success for a Lifetime.

www.deafbilingualcoalition.com

February 12, 2008

We are excited to announce the First Annual Deaf Bilingual Coalition Conference to be held in Milwaukee, Wisconsin June 27 – 30th. DBC is a grass-roots organization established in 2007 to ensure that all Deaf babies and children succeed and thrive through early and strong acquisition of American Sign Language and English.

Currently, 3 children out of 1000 are born Deaf each day in the United States. Many parents are not informed of the marvelous benefits of complete and natural language acquisition and whole child development through American Sign Language. DBC holds strong to the research based facts as well as collective life experiences that babies and children exposed and acquiring fluency in American Sign Language have a higher level of social, emotional, and cognitive well being and development.

It is our goal to promote and celebrate true bilingualism for Deaf babies and children. In order to do so, we need your help. This Conference will be the first of its kind and will bring together people from all over the country and possibly other countries to advocate and learn more about how we all can work together to insure the brightest future for all Deaf babies and children.

In order to do so, we are asking people like yourself who care to become a sponsor of the event or make a financial donation. We are in the process of reserving a Conference location, securing speakers and sponsors. The cost will be between \$20,000 and \$30,000. We are expecting a very large turn-out for this event.

Your donation to this cause will go far into growing State DBC chapters so that a nation-wide system can be established working together with other organizations to ensure Deaf Babies and Children have access to American Sign Language from the start. We are passionate about this mission and appreciate your financial support.

Please send your contributions or sponsorships today to: (All donations are tax deductible.)
Pay Pal via <http://www.cad1906.org> (California Association of the Deaf)

OR...Make checks out to CAD and add DBC on the memo line and mail to:
CAD co CHAD
c/o CA Home for the Adult Deaf
529 Las Tunas Dr.
Arcadia, CA 91007

If you have further questions, please contact deafbilingual@gmail.com

With Sincere Gratitude of Your Support,

The Deaf Bilingual Coalition Core Committee

John Egbert, Ella Mae Lentz, David Eberwein, Barbara DiGiovanni, David Reynolds, Tami Hossler

Facts about Children who are Deaf or Hard of Hearing in Wisconsin

- ⊙ Hospitals in Wisconsin screen newborns before discharge for early detection of hearing loss. One major purpose of this program is to identify children so that they can receive early intervention.
- ⊙ In 2007, there were 95 newborn babies in Wisconsin identified as having hearing loss through the newborn hearing screening test.
- ⊙ Insurance companies are not required to pay for hearing aids or cochlear implants for children who need them.
 - According to a survey conducted by the Wisconsin Families for Hands & Voices, 54% of the parents surveyed did not have insurance that covered any of the cost of hearing aids or cochlear implants.
 - The average out of pocket expense for hearing aids for families with no insurance coverage was \$4,100.
 - Families who had partial coverage of hearing aids paid an average out of pocket expense of \$3,727.
- ⊙ Families in Wisconsin are struggling to pay for hearing aids and cochlear implants for their children. The result is that some families are going into debt, and some children are significantly delayed in receiving intervention or simply do not receive the appropriate intervention at all.
- ⊙ Intervention through hearing aids or cochlear implants can allow a child to maximize their language and speech.
- ⊙ It costs far more in the long-run to educate and support individuals who do not receive appropriate early intervention than to provide it as soon as possible.
 - Research shows that early intervention can provide a savings of between \$5,000 - \$10,000 per child per year in reduced or eliminated special education services¹. And over a lifetime, early intervention can reach a savings of about 1 million dollars per person².
- ⊙ Wisconsin State Employees already have coverage under the state healthcare plan.
- ⊙ Connecticut, Kentucky, Louisiana, Maryland, Minnesota, Missouri, Oklahoma, Rhode Island, Maine, and New Mexico all have laws that require insurance coverage for children who are deaf or hard of hearing.

* This fact sheet was created by Disability Rights Wisconsin in conjunction with Wisconsin Families for Hands & Voices.

¹ Yoshinaga-Itano, Christie, and Gravel, Judith. The Evidence for Universal Newborn Hearing Screening. *American Journal of Audiology*, December 2001: 10: 62-64.

² These figures are based on 1993 numbers as reported by Johnson, J.L., Mauk, G.W., Takekawa, K.M., Simon, P.R., Sia, C.C.J. and Blackwell, P.M. Implementing a statewide system of services for infants and toddlers with hearing disabilities. *Seminars in Hearing*. 1993; 14:105-119.

Thank you Chairman Lasee and Committee members for holding this hearing and for your time this morning.

Our fourth child, John, was born in 2003. At the hospital they did a hearing test before he could be discharged from the hospital. This was new to us; my other 3 children were not screened for hearing loss. I learned that all babies born in Wisconsin are now screened for hearing. **The reasoning behind this testing is because the research is overwhelming and conclusive that early detection and intervention are critical for speech and learning development.** The first 5 years are especially critical. If this window of opportunity is missed, it cannot be made up.

John failed his hospital hearing test and further testing confirmed that he was deaf. John received a cochlear implant at age 1.

A favorite quote of mine: "A cochlear implant is not a miracle, it makes miracles happen". Our family has experienced this over the past 3 years. John is almost caught up with his speech and is cognitively age appropriate. Socially he is blossoming and converses with his family and friends at preschool. He will be mainstreamed in his neighborhood school and start Kindergarten this fall. And although school will still be more challenging for John than my other children, we have hope that he will thrive.

Since John was implanted at age 1, he only had a one-year gap to catch up with his speech and language. What I noticed is that as he 'catches up' and closes that gap, he gets stronger cognitively and he develops socially. So yes, we feel the cochlear implant has been a miracle to John and our family.

That is why I am here today. I witness everyday the life-changing impact that this bill will have on deaf children. Without the cochlear implant, John had no chance of developing speech. He would be isolated from much of the world. And he would not be mainstreamed in a regular classroom environment.

This is what will happen if you do NOT pass this bill: There will be deaf and hearing impaired children that will not get the chance to benefit from the great advances in technology made in hearing devices. They will miss out on hearing and learning to speak in those early, crucial years of development. They will not get a chance to be mainstreamed at their neighborhood school. They will be isolated from other children. They will encounter greater challenges in school and learning. In the long run this will cost the state greater tax dollars. And most importantly, it will close doors to deaf children in a world that relies on hearing.

Please restore our faith that we indeed live a democracy where those that represent us vote on legislation that has their constituents' best interest in mind. That we have **not** become a society where special interest groups dictate or influence our laws. That we are truly a society where no child is left behind. And when we are dealing not only children, but children with special needs, I can't think of a group that needs all of our support more.

In fact, in preparing for speaking at this hearing today, I had intended on addressing some concerns people might have in passing a bill that would provide hearing aids and cochlear implants to children. I came up with NOTHING. I could not come up with one valid reason why hearing devices for children should not be covered.

Deafness is a physical impairment not unlike other physical impairments that are covered by insurance. Certainly the educational, social and emotional concerns for our children provide reasonable support for this legislation to be passed. However, there is also overwhelming economic reasons to cover hearing devices for children. The cost to educate a deaf child is significantly higher than the cost of correcting hearing loss at childhood.

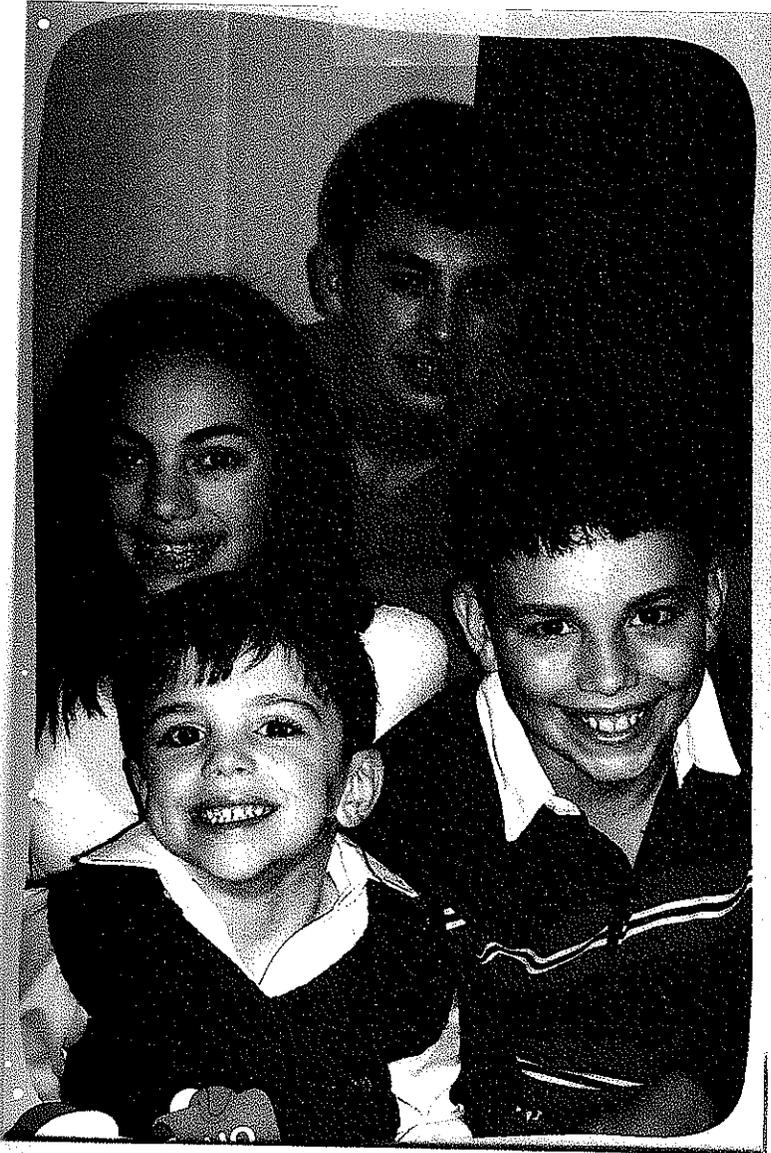
Your vote of yes will only affect a small number of children as there is a low occurrence of deafness, and will be a relatively low cost to insurance companies. But your vote in favor of this bill will have a profound impact on the children it does affect. A vote of YES to Senate Bill 88* will give a world of opportunities to all deaf children. Please vote **YES**.

Thank you again for your time.

Submitted by:
Linda Bonfiglio Schulz
4651 N. Ardmore Ave.
Whitefish Bay, WI 53211
(414) 962-8255

* I preferably support SB-88, but also support AB 133 with the following amendments:

1. Increase the age from 5 years old to any child under the age of 11.
2. Strike "severely" from "deaf and severely hard of hearing".



"A cochlear implant
is not a miracle,
it makes miracles
happen."

John Schultz

Age 4

